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"The design and implementation of surveillance systems to generate valid epidemiological data on deployed forces."

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Hearings Before the
Committee on Government Reform
Subcommittee on National Security,
Emerging Threats, and International Relations
on

Protecting the Health of Deployed Forces:
Lessons Learned From the Persian Gulf War

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Thank you, Mr. Chairman.

I am Manning Feinleib, Professor of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. I was formerly Director of the National Center for Health Statistics at CDC and Associate Director for Epidemiology and Biometry at the National Heart, Lung, and Blood Institute of NIH. I am a member of the Institute of Medicine and have served on a recent IOM Panel on Gulf War and Health.

Today I would like to discuss some aspects of the design and implementation of surveillance systems needed to generate valid epidemiological data on deployed forces.

Following the 1991 Gulf War many groups became concerned about the health of the deployed forces. Several research studies confirmed the impression of the veterans that they were experiencing a variety of symptoms at higher rates than the general population (Joseph 1997, Joellenbeck 1998, Murphy 1999, Kang 2000). However, the studies were hampered by a lack of data on the base-line health of the veterans, lack of objective data on post-deployment health status, and inadequate data on exposures during deployment. Acting on the advice of numerous committees and task forces, and directives from Congress (*PL 105-85 Sec. 765.*) and from the National Science and Technology Council (NSTC 1998), DoD established several programs to improve the health of the military, veterans, and their families. DoD also requested the Institute of Medicine to evaluate

these efforts and several extensive reports were produced providing detailed comments and numerous recommendations. (IOM 1996, 1998, 1999a, 1999b, 2000) Recently, analyses of the data generated from these efforts have begun to appear (MSMR 2002a, 2002b).

It is my overall impression that although some initial steps have been taken to carry out this important mandate, implementation has been fragmented and little worthwhile data will be forthcoming from the forms currently used for pre- and post-deployment health assessment.

As used by epidemiologists and public health workers, surveillance is a process for monitoring the health status of defined populations by collecting, analyzing, interpreting, and disseminating information about the occurrence of diseases in these populations. The various expert committees have been unanimous in recommending that the type of surveillance most suitable for studying emerging health problems in deployed forces is the prospective cohort study. At the time of deployment and immediately upon returning from deployment, a roster of all deployed personnel would be obtained and their baseline health status would be ascertained by means of standardized questionnaires and interviews supplemented with medical examinations and laboratory studies where indicated. During the period of deployment, data would be obtained on potential hazardous exposures and circumstances that may predispose the troops to future health problems. A tracking system would determine ensuing health events among all of the cohort members as early as possible. Procedures would be in place to verify diagnoses

and make referrals to appropriate health care facilities. In order to identify and determine the impact of specific exposures, various comparison groups would be assembled concurrently and followed in a similar manner to the deployed personnel.

Congress has already mandated this tracking system in the National Defense Authorization Act of 1998 (PL 105-85 Sec. 765). More detailed descriptions of the tracking system and strong recommendations to implement such longitudinal cohort surveillance was made by the IOM Committee on Measuring the Health of Persian Gulf Veterans (IOM 1999a) and the IOM Committee on Strategies to Protect the Health of Deployed U.S. Forces (IOM 2000), chaired by Dr. John Moxley. The Committees recognized the great challenge this presented and that it would require the collaboration and commitment of both the VA and DoD, and possibly other agencies. A key requirement for the success of this endeavor would be obtaining the continuing participation of the deployed personnel for many years after their deployment. The Committees emphasized that this approach could eliminate major problems that were encountered in trying to resolve many of the veteran health issues that arose following the Vietnam and Gulf Wars.

I vigorously second this recommendation and urge that adequate direction and resources be provided to implement it effectively.

From an epidemiological perspective, cohort surveillance in the military setting offers some formidable challenges but also unique opportunities. I would like to go over some of these in the next few minutes.

1. **Purposes of a surveillance system for deployed forces**. In designing a surveillance system it is desirable to start with a clear concept of the purposes of the system, what questions it will be used to answer, and what are the population and subgroups of interest. There are many parties concerned about the health of veterans and the purposes for and questions to be addressed by the surveillance of deployed personnel are therefore many and varied. For some of these purposes it may not be necessary to track all of the deployed personnel and appropriate samples of the population may provide desired information in a more efficient and timely manner. Basically the purposes of surveillance include the following elements:

    1. To ascertainment health status immediately before and after deployment.

    2. To document exposures to known or potential hazards.

    3. To provide an opportunity for personnel to express concerns about their health and receive early medical attention.

    4. To ascertain health events after discharge, including physical, mental, and reproductive effects. The experience of Viet Nam and the Gulf War indicate that potential effects may be both subtle and complex, and may take several years to manifest themselves.

    5. To compare the nature and frequency of health events among groups with different exposures.

The Pre- and Post-deployment Health Assessment forms try to address the first and third aims.

2. **Obtaining accurate, timely, and complete information at baseline**. Although the cohort of deployed personnel is inherently well defined, obtaining accurate, timely, and complete information on all of the participants has not been achieved despite strenuous attempts to do so. Recent reports from the Army Medical Surveillance Activity (AMSA) highlighted some of the deficiencies of the recent experience in using the Post-deployment Health Assessment forms (MSMR 2002a, MSMR 2002b). Only about one-third of completed pre-deployment forms could be matched with post-deployment forms. The information was incomplete and the question on exposure concerns, in particular, seemed to be misunderstood by many of the respondents. All positive responses about health concerns should be followed up with more detailed interviews and medical examinations but apparently are not. Obviously, it would be desirable if all of the forms could have been linked to records of sites of deployment and specific exposure information obtained during deployment. This would eliminate biases in recalling putative hazardous exposures if sought after the occurrence of illness.

3. **Assembling comparison groups**. The key analytic comparisons to be made are of subsequent health events among personnel with different histories of exposures. In addition to the exposure information obtained for deployed troops, it would be desirable to assemble comparison groups among military personnel who were not

deployed and among reserve units that were not activated. These would allow, for example, estimates of the health impact of deployment among those without specific exposures.

4. **Active and passive surveillance**. The ascertainment of symptoms and illnesses after discharge is a formidable task and would require a great deal of effort and resources. Passive surveillance, the ascertainment of health outcomes from routinely collected administrative data might be possible for veterans using the VA health systems but would be extremely difficult for those using private sector health care providers. A system of active surveillance, periodic contact with the veterans, would be more feasible but presents major challenges. Contact by telephone or mail requires maintaining an up-to-date roster of addresses and phone numbers. Obtaining the long-term cooperation of the veterans, following up on positive responses, and providing feedback to the participants would be important components of the tracking system. It will be important to clearly explain the purposes of the study and to provide assurances of confidentiality.

5. **Disease definition**. Most epidemiologic studies have a relatively clear concept of the outcomes they are concerned with and go to great lengths to establish standards for defining these outcomes. One of the lessons learned from previous deployments is that new symptoms and diseases may occur following deployment that do not fit into current classification systems. These may involve physical manifestations as well as psychological ones. It is important that methods be in place to capture these emerging

conditions and analyze them properly. Concerns have also been voiced about possible effects on the families and progeny of the veterans from possible residual contamination after discharge or from genetic effects of noxious exposures.

6. **Medical records**. Most of the expert committees stressed the importance of upgrading the medical record keeping capacity of the surveillance system. Methods must be created to obtain information in real time in the field, transfer it to a centrally maintained data repository, and link the information to individual level records. Quality control measures must be in place to assure that all records are accounted for, that individual items are completed, and that editing and coding procedures are adhered to. If systematic deficiencies are uncovered, they should be corrected as soon as feasible. Structural problems in the design of the instruments may be uncovered that require major overhauls. As mentioned earlier, the AMSA analyses revealed a major problem with the question on exposure concerns and recommended major revision of this question. But even such items as sex were not completed for a significant number of forms. An expert group recommended that the pre- and post-deployment health assessment forms be dropped altogether. (IOM 1999b). The Health Enrollment Assessment Review Questionnaire (HEAR) has been suggested as a more useful form. I recommend that the potential of Computer Assisted Personal Interviews (CAPI) be explored as a substitute for paper-and-pencil forms. These may facilitate obtaining more complete and detailed information.

Mr. Chairman, I will close my remarks at this point and will be pleased to respond to any questions you may have. Thank you.

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